Avoiding a tyranny of the majority: Public deliberation, sensitive issues, and vulnerable populations

Open Peer Commentary on "The Rise of Citizen Science in Health and Biomedical Research"

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Brief Bios:

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Citizen science is touted as a means of making science more inclusive and democratic. However, when citizens are drawn from societies with significant socioeconomic and racial disparities, citizen science may reproduce the same structural oppressions that exist in society at large. We use the case of public deliberation on minor consent for HIV biomedical prevention trials to illustrate the potential for structural oppression in citizen science, and then outline approaches to mitigate these concerns.

Public Deliberation as a Citizen Science

Public deliberation is a form of citizen science for controversial health policy issues. In public deliberation, a group of ordinary people (citizens) are assembled for education and a facilitated discussion. This ideally sets the groundwork for a more deliberative discussion that is "informed, value-based, and transformative." (Blacksher et al. 2012) The goal of public deliberation is not consensus, but rather to identify, clarify, justify, and balance competing viewpoints, producing a set of recommendations for policy-makers. (Blacksher et al. 2012) Scientific experts, stakeholders, and policy makers play supportive roles, providing data and education to inform the deliberation. Education and facilitation are key features that distinguishes deliberation from traditional research methods, in which participants are typically asked to respond to questions in light of their existing knowledge about the phenomena of interest. Public deliberation has been used successfully for topics such as biobank consent, vaccines, and setting priorities for public health spending. Public deliberation allows citizens to assess data and make recommendations that can be considered alongside those offered by scientists and policy-makers.

Minor Consent and Public Deliberation

Minor consent to biomedical HIV prevention research raises ethical conflicts that are unresolved. Adolescents bear a disproportionate burden of incident HIV infections, with significant disparities among sexual and gender minority youth and youth of color. (Centers for Disease Control and Prevention 2018) The controversial policy issue is whether minors should be able to self-consent for research that poses greater than minimal risk of harm. Minor self-consent is well established for behavioral HIV prevention, but biomedical prevention research often includes use of experimental medications, which raises concerns about side effects, understanding of complex study designs with placebo controls, preventive misconception, and resulting behavioral disinhibition. (Ott et al. 2013) Although parental consent has been considered the cornerstone of protection for minors in biomedical trials, with sensitive topics such as HIV, parental consent also raises the potential for social harms if sensitive information (e.g. sexual behavior, gender identity) is disclosed to the parent during the consent process or the study. Youth express strong preferences for self-consent to avoid the potential for such inadvertent disclosures. (Alexander et al. 2015, Knopf, Ott, et al. 2017) Conversely, parents feel strongly about being included in the consent process, and investigators, institutions, and Institutional Review Boards (IRBs) are conflicted (Knopf, Gilbert, et al. 2017). While federal research regulations refer to state laws on minor consent, these laws vary considerably and many were written before biomedical HIV prevention existed, making interpretation difficult. (Ott 2008)

Issues raised by minor self-consent lend themselves to public deliberation. There are values issues, such as views on parental authority vs. youth autonomy, sexual and gender norms, and beliefs about the appropriateness of risk reduction for youth where abstinence is preferred. There are also scientific issues that warrant stakeholder education, namely, that HIV is a treatable chronic illness, HIV is not as transmissible as once believed, and HIV treatment medications can be used for HIV prevention. However, there are potential ethical pitfalls to public deliberation with minors and other vulnerable populations on sensitive topics.

Capturing Community

The voluntary nature, small size, and time intensive nature of public deliberation events predispose the deliberation to selection bias. Deliberations are comprised of small groups (10-35) of volunteer deliberants. The events are time intensive, lasting from one to four days. (Degeling, Carter, and Rychetnik 2015) Such bias has been observed in other ethical arenas. For example, community representatives on IRBs are often not reflective of the communities targeted by research. This is especially true when the phenomenon of interest is highly stigmatizing (e.g. HIV, substance use) and/or the target research population is poor or marginalized.

The potential for selection biases raises the ethical concern of determining who speaks for the community. Random stratified sampling is often used for deliberations on issues that affect all segments of society relatively equally, such as childhood vaccination. When issues affect only a small segment of the community, traditional sampling methods may produce recommendations

that are acceptable to dominant cultural groups, but not the groups most affected by the phenomenon of interest. For example, minors most at risk for HIV, and therefore most likely to be eligible for a biomedical prevention trial, are primarily from racial, ethnic, sexual, and gender minorities. (Centers for Disease Control and Prevention 2018) There are geographic "hot spots", cities and neighborhoods within cities, with a disproportionate incidence of youth HIV. Random stratified sampling may result in a group of deliberants that has little representation from these vulnerable groups or high prevalence areas, and sampling approaches will need to specifically target those at risk.

(Mis)Perceptions about Youth

Deliberations on sensitive topics with marginalized populations raise the potential for implicit bias to influence the discussion and resolutions. Of concern for racial and ethnic minority youth is the "adultification" of minors (e.g. treating minors as adults rather than children, ignoring adolescents' developmental needs), and the inappropriate sexualization of adolescents of color by majority groups. (Epstein, Blake, and González 2017) Of concern for sexual and gender minorities are (untrue) beliefs about sexual orientation as a "lifestyle choice" (and therefore immoral), and lack of acceptance of gender expansive youth. (Steinke et al. 2017) Given the strongly held dominant cultural perceptions about these marginalized youth, public deliberation may produce results that replicate structures of oppression, are not consistent with best practices, or increase marginalization. Although careful attention to sampling and education may mitigate this potential, the possibility must be considered ahead of time.

Adolescents have unique vulnerabilities that raise challenges for participation in public deliberation, and their involvement must be done in a developmentally appropriate, respectful, and effective manner. While decision-making research demonstrates that most adolescents have adult-type capacity to consent to research, (Nelson, Stupiansky, and Ott 2016) young people are often deferential to adults in group discussions. Given these adolescents' sensitivity to stigma and marginalization, it may be hard to engage the very adolescents (sexual and gender minority, ethnic minority) who would qualify for an HIV prevention research study.

Giving Voice

Adolescent-adult interactions also raise concerns about youth voice. Many adults hold the strong cultural misconception of adolescents as risk taking, invincible, and incapable of higher order thinking; others may be dismissive of youth. Facilitators will need to be aware of these misconceptions as they resolve disagreements among adolescent and adult deliberants. There is no "correct" perspective on topics where adolescents and adults commonly disagree. For example, while adolescents tend to be less risk adverse than adults, adults may, in fact, be more risk-adverse when making decisions for their children than when making decisions for themselves.

A final ethical concern is assuring that results produced by marginalized minority adolescent deliberants are considered as valid as those produced by adult, mainstream deliberants. An important component of planning will be to assure that the general public and policy decision-makers will give weight to the results of a deliberation by youth and citizens of marginalized

communities. Related to validity of results is ownership of data. Whether ownership of data is held (or shared) by the deliberants, the marginalized community, or the conveners has implications for uptake by policy makers, dissemination and implementation into practice.

Methods & Mitigating Risk

To mitigate the potential pitfalls of public deliberation on stigmatizing health issues with marginalized populations, we propose several strategies. First, the community from which citizens are drawn should be those affected by the health issue, rather than a broadly representative population. Sampling from affected communities may reduce disproportionate representation from the dominant culture, and reduce the potential influence of unconscious biases on final resolutions. Members of affected communities may be less prone to bias against Black, Latinx, sexual, and gender minority youth, as they are more likely to be familiar with the stigma and structural barriers faced by these youth and their real danger of HIV infection. Second, schedule and plan the practicalities of the deliberation to eliminate barriers to attendance, including use of a central locations, considering transportation and child care, and assuring adequate compensation for offset time and lost wages. Third, use highly skilled facilitators who are trained to ensure that all voices are represented. This prevents any one perspective from dominating the deliberation. Discussions should be designed such that all deliberants are treated with dignity, power differences are recognized, and all deliberants given opportunities to have a voice.

A core goal of public deliberation and other citizen science approaches is to engage populations that had been excluded from research, but our analysis suggests that careful attention to the details of implementation are necessary to prevent further marginalization and oppression.

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